

Privacy Statement: Patients, Families and Carers

Why do we collect personal information about patients, families and carers and how do we use it?

Personal information about the patient, including about other health and social care professionals and family and friends involved in providing support and care, is essential in enabling us to provide the care required and to ensure that the needs of patients and their family members and carers (i.e. close friends) are at the centre of all the care we provide. The lawful basis for collecting and using information to provide care to our patients, families and carers is “public task” i.e. the information is fundamentally necessary for us to provide our care. The fact that we are providing health and social care permits us to handle sensitive personal data. This lawful basis permits us to:

- Co-ordinate the care that we offer – both within our Dorothy House team and externally
- Offer wider Dorothy House support to a patient’s family members, including in bereavement
- Provide information to the NHS and other commissioners with whom we hold service contracts
- Audit, evaluate and develop our services
- Different levels of information are held depending on the extent of Dorothy House input.

What personal information do we collect about our patients, families and carers?

Based on the data processing reasons outlined above, we may collect all or some of the types of information below to help us provide the best care possible:

Basic details including name, postal/email address, telephone number, date of birth/death.

Demographic, equality and diversity data

Medical information including NHS number, detailed medical records, prescribed medications; investigation results and information from other professionals involved in care, patient/client service activity.

Other information includes personal and social history and documentation of consultations. Interactions with family members/carers are usually recorded within the patient’s record, but if a family member or carer is receiving more involved support from Dorothy House then a record will be created in their own right as a ‘client’ record – we will ensure that they are aware of this.

Some people will only attend group sessions, using our ‘Open Access’, but we are still providing a health and social care service. We therefore create a record for each person who attends one of our groups and we will update this with attendances and any relevant clinical notes.

Where do we store patient, family and carers information and for how long?

Patient and ‘client’ data is stored on our electronic patient record system called SystemOne. This is a secure clinical database used by many other health and social care providers including GPs in our area. SystemOne data is hosted off-site within the European Economic Area (EEA) which gives a high level of security as all data processed within the EEA is covered by the General Data Protection Regulations.

Under current data protection legislation, all organisations involved in a patient's care have a duty to ensure that information held about them is accurate, up to date and kept secure at all times. Access to records can be audited and can always be traced back because users log-in using unique identifiers and secure access methods.

Currently, SystemOne is not able to either archive or delete patient records as it is a system shared across many health and social care organisations. However when a record of a patient who has died or discharged is accessed after 52 weeks from date of death or discharge, a reason must be provided and the system tracks access to these records.

Access within the Dorothy House team is on a need to know basis. Where volunteers are providing care and support they are regarded as part of the Dorothy House team. All staff and volunteers with access to confidential personal information receive information governance training.

Sharing personal information about patients and clients with third parties

Dorothy House works as part of a health and social care system in our community. To provide the safest, highest quality, most integrated patient and client care we can, sharing of health and social care information is encouraged, whilst confidentiality is respected. We believe that you would expect us to share relevant health and social care information with other services/organisations involved in your care, or who you have agreed should become involved and will inform us if you do not wish for this to happen. We do not generally share information for clients, or for those who only attend our 'Open Access' groups, but for patients, those we would anticipate sharing information with as part of your care are

- Community care professionals, e.g GPs, District Nurses, Multi-disciplinary teams; Specialist Nurses; Community Matrons
- Hospitals
- Public/private health and social care providers

Although we would always aim to only share the minimum information required, when sharing is via SystemOne (https://www.dorothyhouse.org.uk/wp/wp-content/uploads/2019/01/751-2016-consent_to_share.pdf) this is not always technically possible. We can however ensure that individual elements are not shared, so please tell us if there are particular areas that you wish to remain confidential. Patients do have the right to totally opt out of Dorothy House sharing their electronic patient record with other health and social care providers.

Very rarely we may be required to share confidential personal information without consent if we are required to do so by statutory law, such as if safeguarding concerns

We are required to share information for commissioning; service planning and regulatory purposes with

- Clinical commissioners of local services
- Care Quality Commission and other regulatory bodies
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We will ask, specifically, for your consent (lawful basis) if personal data is to be used for the following:

- Referring our patients / clients on to other service providers (non-health/social care)
- Requested by solicitors or insurance companies

In order for us to raise awareness of our work it is extremely useful to be able to use stories and photographs/video of our patients and their families. We will only ever do this with your specific consent (lawful basis).

Your Rights

In addition to 'Your Rights' outlined in The Overarching Privacy Statement, you also have the right:

- to identify specific areas of information as confidential
- to opt out of Dorothy House sharing your electronic patient record with other health and social care providers (https://www.dorothyhouse.org.uk/wp/wp-content/uploads/2019/01/751-2016-consent_to_share.pdf)
- to sign up for the National Data Opt out <https://www.nhs.uk/your-nhs-data-matters>
- Families and carers can also opt out of receiving any communication offering support in bereavement if they wish to – please inform us if this is the case

If you wish to discuss or learn more about the above please ask your Dorothy House Professional or speak to the Clinical Coordination Centre on 0345 0130 555